The Treatment and Management of Duchenne Muscular Dystrophy at Regency Park Centre, South Australia

This paper describes the treatment and management of boys with Duchenne Muscular Dystrophy at the Regency Park Centre for Young Disabled in Adelaide, South Australia. We have not been convinced that some of the active management programmes advocated elsewhere are effective. Our philosophies and practices reflect a relaxed environment which emphasises achievement and freedom of choice.

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Muscular Dystrophy is an inherited progressive degenerative muscle disorder of which the commonest and most severe form is Duchenne Muscular Dystrophy (DMD)

The following clinical course characterises DMD (Vignos 1968):

- Onset in early childhood, usually in the first five years.
- Symmetrical involvement, first of the pelvic girdle musculature and later of the shoulder girdle.
- Usually enlargement or pseudohypertrophy of the calves.
- Loss of independent ambulation by age nine to eleven years.
- Slowly progressive generalised weakness, often scoliosis.
- Death from cardio-respiratory failure in the late teens or early twenties.

Almost all boys in South Australia with Duchenne Muscular Dystrophy attend the Regency Park Centre as day students from the time when ambulation becomes difficult. As the condition progresses the adolescents have access to the residential facilities of the Centre.

The aim of this paper is to consider the management of the boy with Duchenne Muscular Dystrophy (DMD), particularly when he is no longer strong enough to walk and is reliant on a wheelchair for mobility The philosophies and practices at the Regency Park Centre may differ in a number of respects from other centres where a more aggressive therapy approach is used.

At the time of writing there are 24 boys with Duchenne Muscular Dystrophy at the Centre and another 4 boys who visit periodically from the country. The latest ascertainment shows that there are 38 known cases of Duchenne Muscular Dystrophy in South Australia, including younger boys who are still coping with normal school and some who are totally bedfast at home or in a nursing home. Most of the boys with Duchenne Muscular Dystrophy will come to, or are already attending, Regency Park Centre. They usually start attending the Centre when their physical function has deteriorated so far that they walk with increasing difficulty and have frequent falls. This usually occurs between 9 and 11 years of age. Occasionally, affected boys come to the Centre at an earlier age, parents opting for the more sheltered environment. At the time of writing there are two such boys, both of whom are mobile without orthoses or a wheelchair.

Of the 24 boys attending the Centre, four have manual wheelchairs, one has a battery-powered tricycle and seventeen are confined to electrically-powered wheelchairs. Two of the boys with manual wheelchairs use them for outings so they can 'keep up' with their class, but they are functional walkers about the Centre, one with the aid of orthoses and one without. The other two boys in manual wheelchairs are over 16 years of age and are unable to walk. They propel themselves with their feet or hitch a ride with their friend in an electric wheelchair, but they will not use an electric wheelchair of their own. It would appear these two boys are denying their worsening condition and this manner of coping is accepted by the staff who, nevertheless, let the boys know an electric wheelchair is there if they want it. The boy with the battery-powered tricycle uses it for long distances and walks without orthoses for short distances. An electric wheelchair is unacceptable to him at the present time as this means he has 'the same diagnosis as his older brother'.

Medical Treatment

The cause of DMD is not known and there is, therefore, no specific treatment. A suggestion was made that Allopurinol may be useful in DMD, but a 12-month trial of the drug under double-blind conditions concluded it did not alter the progression of the disease (Stern *et al* 1981).

At the Centre, regular pulmonary function tests are performed. Postural

drainage and antibiotics are used in the treatment of respiratory infections. There is, however, no evidence that regular breathing exercises are effective in delaying respiratory failure in DMD. We are now planning to evaluate the effectiveness of endurance training for respiratory muscles.

It seems that the possibility of reducing the incidence of this terrible disease relies entirely on genetic counselling which in turn depends on the efficiency of the methods for carrier detection. A female at risk cannot be reassured she is not a carrier even when all available tests are normal. At the time of writing, the medical director of Regency Park Centre, Dr. L. M. Stern, is undertaking a study using computerised tomography to try to improve detection of female carriers.

The Centre

Regency Park Centre for Young Disabled is situated on 4½ hectares of land, six kilometres from the heart of Adelaide. It is a treatment and educational centre catering for disabled young people from 3 to 25 years of age with a variety of physical disabilities including cerebral palsy, spina bifida and neuromuscular disorders. Children may attend the Centre as day students or as outpatients. They may also reside in one of five villas.

Residential Facilities

The Centre provides accommodation for up to 60 children in five villas with a houseparent in each villa. Motel type accommodation is available for parents of country children, enabling them to participate in assessments, treatment programmes, and parent support meetings. A ten bed infirmary is also available.

These residential facilities are welcomed by most parents of DMD children and the boys themselves. The villa accommodation permits parental relief from caring for their child and relief for the boys from travelling every day. Some metropolitan boys are weekly boarders; country boys are term boarders. Others come in only for recreational purposes during school holidays, or for brief periods to gradually introduce them to villa life. As an alternative to villa residence there is a State Government Home Visit Nursing Service.

Transport

The boys with DMD participate in a number of activities involving visits to other schools, school outings, recreation and community skills programmes. Daily transport to the Centre for these activities is provided by the Centre's fleet of buses which are equipped with loading platforms for wheelchairs.

Regency Park Centre Special School

The school caters for Pre-school, Junior Primary, Primary and High School students. Although the Centre is administered by the Crippled Children's Association, the school is run by the Education Department of South Australia. The curricula followed in the school are as near as possible to those of regular schools. However, educational programmes are individualised so that the special needs of students can be met. As a group, boys with DMD have a reduced I.Q. (Coulter 1981), although many have average or above average intelligence. It is important that a child who feels inadequate physically, in relation to his peers, is not exposed to repeated academic failure.

Rehabilitation Engineering

There is a well-equipped and innovative Rehabilitation Engineering Department at the Centre (Seeger and Doble 1980). It provides technical equipment including orthoses, special seats, standing aids, walking aids, aids for activities of daily living, biofeedback devices and communication aids. The staff comprises a Rehabilitation Engineer, orthotists, bootmakers and technicians. There is an active research and development programme. A rehabilitation engineering clinic is held monthly and serves as a forum for discussion prior to the manufacture of seats and other special devices and as a means of reviewing their effectiveness. The Clinic is attended by the medical director, an orthopaedic surgeon, the rehabilitation engineer, an orthotist, representatives of physiotherapy, occupational therapy and nursing and the health professional who has referred the patient to the Clinic. The patient is asked to give his views, and although advice is always given by the professional staff present at the clinic, the decision is up to the patient and/or his parents.

Hydrotherapy

There are 2 heated swimming pools at the Centre which are used both for therapeutic purposes and for recreation. Qualified swimming instructors are provided by the Education Department, and a pool attendant carries out hydrotherapy under the supervision of a physiotherapist. The warmth and buoyancy of the water allows contractures to be stretched more easily and allows the boys to move more freely. If the boys are loathe to attend physiotherapy as frequently as required, an extra session in the pool will often be tolerated more readily. If the older boys feel that the discomfort of being undressed and shifted from chairs outweighs the pleasure of the pool, they can choose to have hydrotherapy dropped from their programme. Choice is a very important issue for the wheelchair-bound DMD boy. At a time when other adolescent boys are looking toward gaining more power over their lives, these boys see their options being reduced. To offer them choices gives them a sense of having some control over what happens to them.

Physiotherapy

Physiotherapy treatment is based on the following three principles (Ziter and Allsop 1976):

1. Some of the complications which magnify the functional disability of DMD are predictable and, while not preventable, can be delayed.
2. Regular physiotherapy and the timely application of orthoses can prolong independence and achieve greater comfort.
3. If an effective treatment ever becomes available those in optimal physical condition are most likely to benefit.

Increasing muscle weakness and the development of contractures are predictable in DMD. As contractures are to a certain extent preventable and reversible whilst muscle weakness inevitably progresses, the physiotherapy programme concentrates on passive stretching of muscles and tendons and the prophylactic use of orthoses. However, if the older boys (around 15 years) reject the discomfort of orthoses and therapy, continued treatment is not insisted upon. It is very difficult to maintain enthusiasm towards therapy when traditional reasons are not relevant (*eg* 'It will help you to get better'). 'To slow the rate of deterioration' is a very subtle point for young people to grasp.

Whilst the boys are ambulant, stretches to the tendo Achilles and hip flexors are carried out. Parents are instructed in stretching techniques and advised on prone lying for periods at home. Boys with DMD can typically remain ambulatory without assistance until the age of about 8 years. At the Regency Park Centre each family is assisted with the difficult decision of the use of long-leg calipers to prolong ambulation. One must weigh the effort required for adjustment to and continued use of braces against the relative ease of a wheelchair existence. It is easier to cope at the Centre than at normal school with ring-topped long-leg calipers, since there are trained staff to assist and to give continued reinforcement.

Once the boy is confined to a wheelchair, muscle stretching by positioning, active muscle stretching and prophylactic application of orthoses to slow the development of contractures are advocated at the Centre. During the day the boys wear light polypropylene ankle-foot orthoses cast in the maximum attainable dorsiflexion.

In practice we find most boys accept the day splints quite cheerfully because of the cosmetic appeal of normal looking feet. Having feet plantigrade ensures that their feet rest with even pressure distribution on the footplates of their wheelchairs and they can wear normal shoes. Sometimes releases of the tendo Achilles and even tibialis posterior transplants have to be performed so that this can be achieved. Those who will tolerate them wear either night splints made of plaster-of-Paris or polypropylene lined with Plastazote. However, as their nights are already disturbed by cramps and nightmares and the need to be turned often, most boys will not persevere very long with night splints.

The authors have been measuring and recording the effectiveness of these various treatments as methods of slowing the progression of equinus deformity. The measuring device is an electronic ankle angle goniometer with pivots aligned to the anatomical ankle joint axis. It measures the difference between the plantar surface of the foot and the anterior surface of the tibia. Results of a 12-month study at the Regency Park Centre indicate that gains from passive stretching and wearing orthoses can be lost during a long vacation without professional supervision.

Attempts are made to maintain range of movement by stretching pronators, wrist flexors and long finger flexors (which get very tight resting over the wheelchair control switch). Hand splints are sometimes used at night to maintain range and prevent further deterioration. Therapists also pay particular attention to abduction of the shoulders and generally encourage the boys to use their upper limbs while they still can.

At Regency Park doctors and therapists use a Functional Evaluation Form for muscle disorders (Appendix 1). It includes a functional classification which has been adapted from Vignos (1968). The limitation of this grading system is that it reflects mainly the strength of the lower extremity. There is however, in muscular dystrophy a proportional loss of strength of the upper extremity concomitant with weakness of the lower extremity. The Functional Evaluation Form allows for shoulder and forearm function to be monitored by serial measurements of active shoulder abduction and forearm flexion. It does not include general functional mobility after cessation of walking because we do not wish to draw attention to a worsening ability.

Mobility on Wheels

When functional walking ceases, even if they continue to walk as a therapy exercise, the boys are immediately provided with an electric wheelchair so that they still have independent mobility. This is in line with Gardner-Medwin's (1979) view that the provision of a well chosen wheelchair gives the boys much more practical independent mobility than does 'bracing for ambulation'. It appears that the loss of ambulation is easier for the boys to bear when an electrically-powered wheelchair is provided straight away. A functional loss has been acknowledged, but at the same time a way of overcoming that loss has been provided. A manual chair just has the student waiting for the next loss. The electric wheelchair gives them the power to act out anger over their loss of function. They have traditionally been durable, heavy chairs for use around the Centre. Now the

tendency is towards lightweight folding chairs as this facilitates integration into the community. They are also more manoeuvrable in the boys' homes, reducing the need for home alterations.

Due to increasing hip and knee flexion deformities and the increased effort needed to stand, most boys prefer not to use a standing frame for much longer than six months after obtaining an electric wheelchair.

Seating

At the same time as the leg muscles of these boys become too weak for walking, the spinal muscles are becoming too weak to hold the spine erect. The motley assortment of cushions and pieces of foam which have to be removed, remembered and replaced whenever the patient is transferred from the chair have now been superseded by a number of alternative techniques to try to support their spinal posture when they are wheelchair-bound. Modular seats provide a firm base and lateral spinal supports (Figure 1). They are available in four base sizes and four back sizes, and they can be covered with foam for comfort. Alternatively, a custom-moulded spinal jacket can be fitted, having the advantage of being inconspicuous since it is worn under the clothes. Or a seat can be custom-moulded to provide intimate support, maximum comfort and relief of localised pressure. A mould is obtained by making a cast of the patient using the vacuum consolidation technique (Seeger 1980) and by recording the resulting impression using plaster-of-Paris. The seat is then vacuum-formed over the mould. It has a soft non-absorbent foam for the lining and hard semi-rigid outer shell. These custom-moulded seats can be lined with sheepskin and the side can be made to pivot away for easy access.

Figure 1: Modular seat in use

The effectiveness of spinal supports has been investigated (Seeger and Sutherland 1981), by measuring lateral thoracolumbar spinal curvature from 6-monthly X-rays. Figure 2 shows the spinal curvature from 0° to 80° along the vertical axis, and age along the horizontal axis. This graph shows the consistent history of the progression of spinal deformity in DMD: a rapid and consistent increase in spinal curvature after the age of 12 years.

A subsequent study found no significant difference in spinal curvature whether the boys had an unmodified wheelchair, a modular seat, a spinal jacket, or a custom-moulded seat (Seeger, Sutherland and Clark, in press). There was a significant progression of spinal curvature beyond the age of 12 to 14 years regardless of whether a spinal brace was used. This finding supports the view of Johnson (1980) that: 'There is absolutely no corrective ability by a spinal brace in paralytic scoliosis associated with Duchenne Dystrophy, in my opinion'. It would appear that seating comfort should be the main consideration in prescribing spinal support for boys with DMD.

Researchers at the Hospital for Sick Children in Toronto (Koreska *et al* 1977) have claimed the value of fitting a lumbar pad to increase lordosis in order to prevent scoliosis. We have no experience of this technique at Regency Park. Further investigations of this claim have been carried out at Regency Park Centre by taking X-rays with and without a lumbar pad and applying known forces to see how much lateral bending is induced. Our initial results have failed to support the view that the lumbar spine is more resistant to lateral bending when it is placed in extension.

On the basis of these findings the orthopaedic surgeon responsible for these children is looking more favourably at spinal fusion techniques while the boy's vital capacity is adequate to cope with the anaesthetic and the

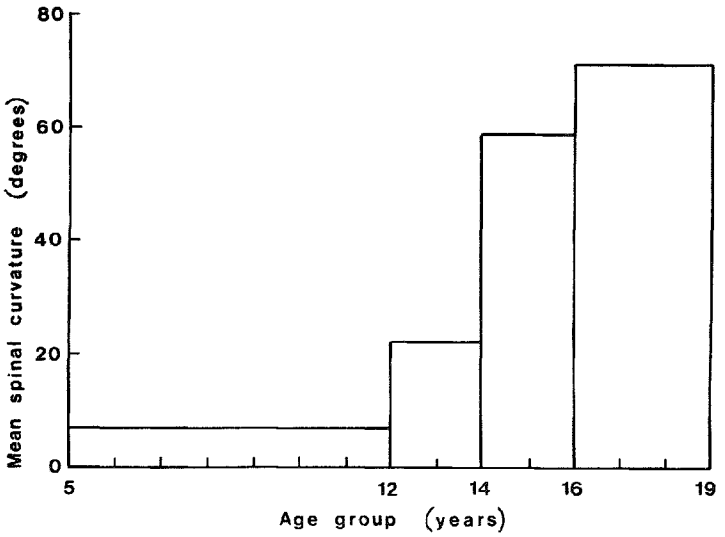

Figure 2: Progression of spinal curvature in Duchenne muscular dystrophy The mean spinal curvature is shown for each of 4 age ranges

rigors of a major operation. We believe that a new technique of internal fixation, in which wires are attached to the vertebrae and looped around a contoured rod, may be the only effective means of managing scoliosis in Duchenne muscular dystrophy. Where bracing or special seating are used their function must be to improve the child's comfort

As the progressive paralytic collapsing scoliosis makes seating increasingly difficult and increasingly uncomfortable, the goal of seating changes from postural support to distributing pressure, using for example a ROHO dry flotation cushion.

Daily Living Skills and Recreation

At the age of approximately 15 years, the boys' educational programme changes from an academic one to an 'experiential' type. There are some elements of formal teaching but mostly the boys choose how they will spend their time. At this age they are given the option to stay home one day a week, which gives them a chance to conserve their energies for the things they like to do most. Also, for them, this becomes a subtle way to 'beat the system', and it gives them choice. The Centre has two Activities of Daily Living (ADL) flats and the boys spend some time cooking and housekeeping — they suggest ideas and the occupational therapist or teacher assists in the implementation. There are various devices to help the boys in activities of daily living. Two boys use a mobile arm support for eating and other activities, but most of the boys do not like special equipment which makes them 'different'. It seems to be important for them to use the physical skills they have left, however minute.

They prefer, for instance, to direct a person to put food in their hand and then lift their arm to their mouth, demonstrating that they still have some control over their own bodies. For the same reason, most of the boys dislike the use of domestic hoists and would rather direct staff how to lift them. Parents are also very resistant to the use of domestic hoists, using them as a last resort when their own physical condition prevents them from lifting. Therapists have a role to play in advising parents on suitable home management.

In technical studies classes, the boys initiate and the teacher finds ways of involving them, *eg* easy woodwork, sanding, using electrical equipment. The boy plans but needs help in construction. However, he does what he is able to do physically. Some have completed electronic projects from commercial kits and this involves reading a plan, recognising components and soldering. Other activities they can cope with physically and which improve their quality of life are the use of computers, Citizen Band radios, video recording machines, T.V. games and Hi-Fi stereo. They have also set up a radio-controlled car club.

The pension becomes a very important element in the boys' lives when they reach 16. They then have some economic independence and they can make practical decisions about what items to buy to improve the quality of their lives. Weekly outings without adult supervision are arranged to view films, attend concerts, go shopping or girl watching. There is recognition that the boys are not asexual. They can buy 'girlie' magazines like other adolescent boys. Once a fortnight the experiential group spends a night in the ADL flat with a male aide — cum bus driver — cum friend and quite literally have a 'night out with the boys' playing cards, staying up very late and tasting some small measure of independent living.

Since the boys have been given some power to choose, and staff have secured their trust, they have devoted less energy to 'testing the limits' and acting out their frustrations.

Sport is very important to the boys and they spend four hours a week playing balloon soccer in their wheelchairs (Figure 3) and balloon tennis.

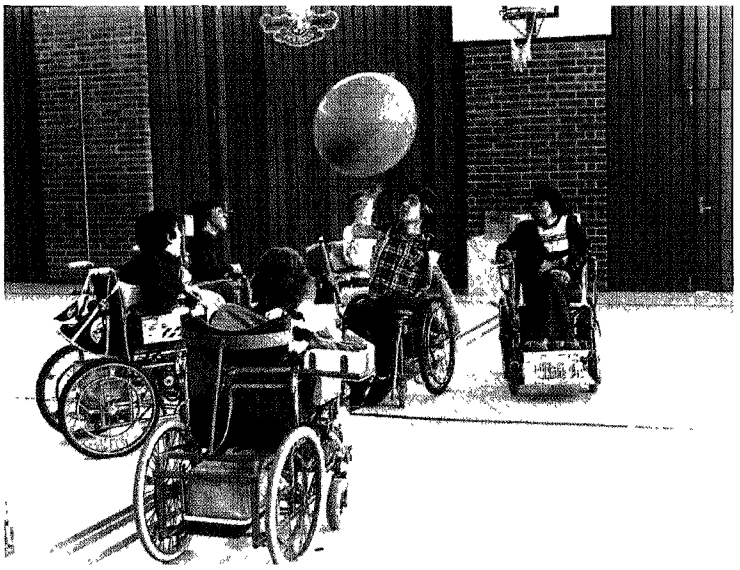

Figure 3: A game of balloon soccer in progress

Australia is a very sport orientated society and such activities allow the boys to be part of that society. It is an acceptable channel for aggression, encourages teamwork, and helps them cope with winning and losing. It involves skill and tactics and they can play against able-bodied people. It also encourages socialisation and gives them more to live for. They feel good or bad after a game and at least know they are alive. In some cases, it has been thought that a game of soccer may be the only pleasure in life. The Education Department of South Australia has given a grant to make a video recording of a game emphasising the boys' ability rather than disability.

Psychological Problems

In November 1981, staff from different disciplines who were involved with the muscular dystrophy students at the Centre formed an Interest Group in recognition of the particular problems of these students and of the staff who have to cope with them The aim of the group is to share ideas and experiences, to chronicle the present policies followed in the management of the students with DMD and to suggest changes if people felt they were necessary Some of the dilemmas are listed below.

Purpose of the Programmes for DMD boys

The knowledge that they are dying affects the students' attitudes to work. They see no point in much of their schooling, therefore they do not wish to do it. Should the teacher make no demands on them in their primary years or give them as many options as possible so they can make real choices later on as to how to spend their time? They need to learn to read if possible, so that an increased range of leisure activities is open to them. The optimum time for learning to read comes often when they are losing physical abilities and most of their energies are being used to combat the trauma of their loss.

Choice and Power

It is important that the boys be presented with genuine choices within their programmes so they can make decisions. The boys need to feel a sense of power and the most effective way of using power is to choose to refuse to co-operate with the system. Therefore, however much effort is put into giving these students choices, the only ones they are interested in are those that cause problems. Nursing, medical care and therapy have to be done at a particular time for reasons of staff timetabling. Large amounts of time are therefore non-negotiable and the balance between student choice and staff duties is delicate

Motivation and Denial

In the primary school classes, they want 'normal experiences' and to be treated like the other children who have non-progressive conditions. Their prognosis is not dominant in planning a programme for them. In the senior school, there is no denial of the prognosis and consequently the programme must be intrinsically motivating.

Parents

Obviously the parents' attitudes affect the child's understanding and handling of his feelings. In the senior school the boys are protective of their parents and understand clearly what the parents can handle and avoid painful subjects accordingly. A parent self-help group was formed in 1981 at the Centre by the Family Services Unit (psychologists and social workers) at the request of some parents of primary school children with DMD and spinal muscular atrophy. An additional support group to which some parents belong is the South Australian Branch of the Muscular Dystrophy Association.

Death and Dying

Previously, when the boys with DMD became bedfast and death

seemed imminent, they were transferred to the nearest large hospital. However, it was considered that we were failing our students at the time when the need was greatest. A new and exciting policy has now been established that the boys who are in terminal stages of their disease will not be removed to an environment which is totally foreign to them but will be allowed to die in the Infirmary of the Centre Whilst the staff involved at the time may find it a strain to counsel the families at a stage when their children are dying, it also must be seen as an important way for the staff to work through their own reactions since, having spent considerable amounts of time with these boys, they undoubtedly become very attached to them.

Conclusions

Those of us who are involved with the treatment and management of children with DMD cannot help but identify and share a little in the protracted grieving process that the boys and their parents go through from diagnosis to death. It is important that these children and young adults are not unnecessarily subjected to active management programmes whose effectiveness has not been evaluated We would rather see a more relaxed environment which emphasised achievement and freedom of choice. We have at all times tried to maintain a questioning approach to our management, and above all have taken the wishes of the boys and their parents as our prime concern At Regency Park Centre we encourage the patient's individuality, while not denying his dependence. We seek to provide a setting which maximises his potential for living and in which he can find his own best way of relating to the external world and to himself The words of Howard A. Rusk are particularly appropriate: 'We have added years to their life, now it is our responsibility to add life to their years'.

Acknowledgements

The authors acknowledge contributions by Mr D. Evans and the Muscular Dystrophy Staff Interest Group, and thank Dr D. J. Caudrey, Dr L. M Stern and Mrs M. Denton for their helpful comments on an earlier draft of the manuscript.

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Appendix 1

REGENCY PARK CENTRE FOR YOUNG DISABLED CHILDREN
MUSCLE DISORDER FUNCTIONAL EVALUATION FORM

NAME D O B

DIAGNOSIS

ABBREVIATIONS FOR NOS 8 11
0 — No assistance needed
Rh — Right hand for assistance
Lh — Left hand for assistance
R — Railing for assistance
K — Extends knee with hand
Bh — both hands for assistance

DATE				
1 Functional Class/Age (see Classifications)				
2 Standing/walking (hours per day)				
3 Height (cm)/percentiles				
4 Weight (kg)/percentiles				
5 Peak expiratory flow rate (PEFR) (in litres/min)/normal range				
6 Pulse rate				
7 E C G				
8 Stair climbing TIME (7 steps of 18 cm)				
DESCRIBE (abbreviations as per list)				
9 Rising from Floor TIME (backlying to standing position)				
DESCRIBE· (abbreviations as per list)				
10 Rising from chair TIME (45cm height chair or if lower cha. used state height in cm)				
DESCRIBE (Abbreviations as per list)				
11 Walking (10 metres) TIME.				
DESCRIBE· (Abbreviations as per list)				

DATE	L	R	L	R	L	R	L	R
12 Active neck flexion (0 5)								
13 Active shoulder abduction (0 5)								
14 Active forearm extension (0 5)								
15 Active hip extension (0 5)								
16 Active knee extension (0 5)								
17 Active (therapist's choice)								
18 Range of joint movement (passive) Neck extension (0 80°)								
Elbow flexion (0 150°)								
Supination of forearm (0 90°)								
Hip flexion (0 120°)								
Knee flexion (0 135°)								
Ankle dorsiflexion (0 20°)								
19 Contracture of tensor fascia lata (Yes/No)								
20 Scoliosis (Direction of curve and apex)								
21 Pelvic obliquity (note high side — L or R)								

ADDITIONAL OBSERVATIONS

FUNCTIONAL CLASSIFICATIONS:

The ten classes of functional ability are:—

1. Walks and climbs stairs without assistance.
2. Walks and climbs stairs with aid of railing.
3. Walks and climbs stairs slowly with aid of railing (over 25 seconds for seven standard steps).
4. Walks unassisted and rises from chair but cannot climb stairs.
5. Walks unassisted but cannot rise from chair or climb stairs.
6. Walks only with assistance or walks independently with long leg braces.
7. Walks in long leg braces but requires assistance for balance.
8. Stands in long leg braces but unable to walk even with assistance.
9. Confined to wheelchair.
10. Confined to bed.